THE GUT
Foundation

UNDERSTANDING ENDOMETRIOSIS, IRRITABLE BOWEL SYNDROME AND CHRONIC PELVIC PAIN

A Guide from
The Gut Foundation

At a glance

Endometriosis, irritable bowel syndrome (IBS) and chronic pelvic pain are common conditions affecting women during their reproductive years.

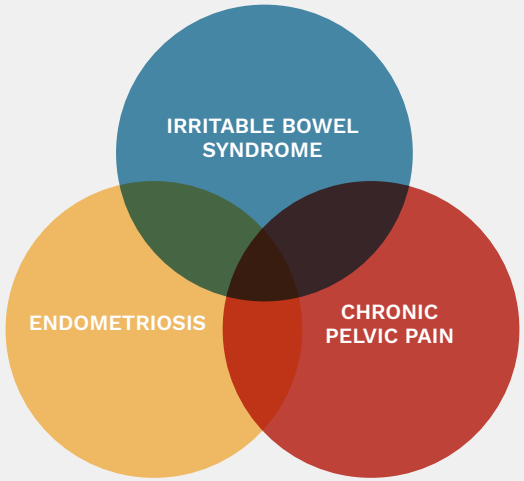
It can be difficult to diagnose each of the conditions, and some of their symptoms overlap.

There are often long delays to accurate diagnosis.

Effective treatments are available.

A response to treatment can confirm the diagnosis.

Information, help and support is available for women experiencing endometriosis, IBS or chronic pelvic pain.

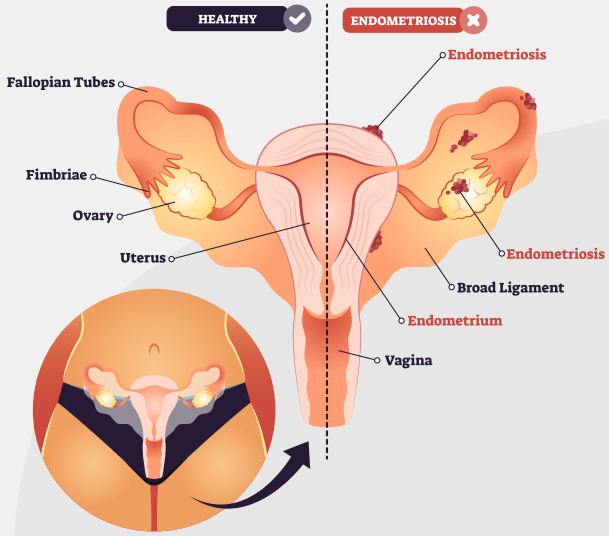


Back to basics

The lower abdomen and pelvic cavity contain organs of the gastrointestinal tract (the colon and rectum), the entire female reproductive system (including the uterus, ovaries and Fallopian tubes) and the urinary system (the bladder). They are protected within the muscular abdominal wall and the bony pelvis. The pelvis is attached to the lower part of the spinal column (backbone).

Problems in any of the organs, muscles, bones and nerves in this region can lead to pain and disability. It can sometimes be difficult to identify the exact problem, so it can take time to make an exact diagnosis and work out the most effective treatment.

FEMALE REPRODUCTIVE SYSTEM



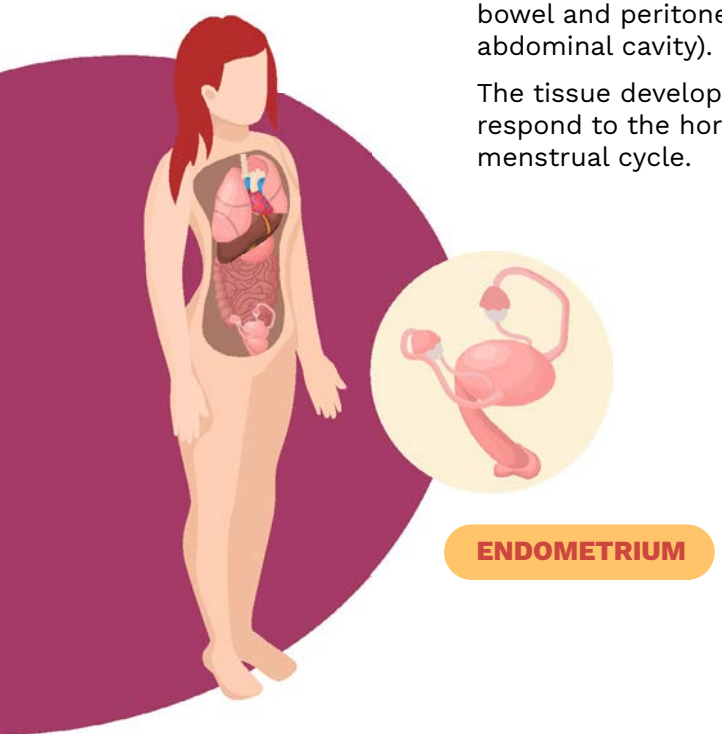
Endometriosis

What is endometriosis?

During the normal menstrual cycle the lining of the uterus (the endometrium) is lost through menstrual bleeding. In many women small amounts of endometrial tissue sometimes move in the wrong direction and escape into the abdominal cavity through the fallopian tubes.

In a minority of women, the endometrial tissue attaches to pelvic organs including the ovaries, Fallopian tubes, uterus, bladder, bowel and peritoneum (the lining of the abdominal cavity).

The tissue develops and then continues to respond to the hormonal changes of the menstrual cycle.



What are the symptoms of endometriosis?

Endometriosis can lead to a wide range of symptoms.

They include:

- Pelvic pain, especially just before and during a menstrual period. Unlike usual period pain, it often does not respond well to standard treatment such as analgesics and oral contraceptives
- Irregular and/or heavy menstrual cycles
- Dyspareunia - pain during or after sex
- Infertility
- Voiding dysfunction – problems with fully emptying the bladder, leaking associated with urgency, pain when passing urine, difficulty holding on when you have a full bladder and having to go frequently
- Pain during a bowel motion
- Other gastrointestinal symptoms, especially bloating, but also nausea, constipation, vomiting and rectal bleeding
- Bleeding after intercourse
- Straining at the beginning, during and at the end of defecation and voiding
- History of haemorrhoids and/or fissures
- Rectal pain during or after defecation
- Difficulties in starting a bowel motion, and in fully emptying the rectum and bladder.

How common is endometriosis?

About one in ten women of reproductive age (that is between the onset of periods as a teenager and menopause) have endometriosis. Not everyone with endometriosis will have symptoms.

How is endometriosis diagnosed?

The history of symptoms, the findings on physical examination and information from an ultrasound of pelvic organs can suggest the presence of endometriosis.

Currently, the only way to make a definite diagnose is to identify abnormal tissue during a laparoscopy. This involves passing a thin tubular instrument through the wall of the abdomen to physically inspect the pelvic cavity.

“The bleeding and breakdown of endometrial tissue each month can lead to scar tissue and adhesions between pelvic organs.”

How is endometriosis managed?

Treatment for endometriosis is carefully adapted to the needs of each individual. It aims to reduce pain and other symptoms, and to improve fertility for women who want to become pregnant.

Due to the impact of endometriosis in the abdominal and pelvic cavity, pelvic floor physiotherapy and physical activity can prove an effective pain management strategy, particularly in Dysmenorrhea (period pain)

Standard medications like paracetamol and nonsteroidal anti-inflammatory drugs such as ibuprofen ('Nurofen') can help control pain. If pain relief is not effective for what sems to be period pain, then it suggests that other problems might be the cause.

A number of hormonal treatments can help to reduce symptoms. Medication which reduces the number of menstrual periods, or stops them completely, can reduce the cyclical changes in endometrial tissue and the resulting symptoms.

They will not get rid of the endometrial tissue that is already in place.

Surgery such as excision surgery with an excision specialist to remove endometrial tissue will sometimes be recommended, both to relieve pain and improve fertility.

Endometrial tissue can re-grow after surgery, so symptoms can occur again after a few years.

If the disease causes severe problems and has not responded to other treatments, then some women will consider hysterectomy. This decision should not be taken lightly, and it is important to note that this may or may not solve the problem, with some women's pain persisting after hysterectomy.

"Hormonal treatments include standard oral contraceptive pills, progesterone-like medications, and gonadotrophin-releasing hormone agonists which regulate the menstrual cycle. The choice of the best medication will depend on person's exact needs."

Irritable bowel syndrome (IBS)

What is IBS?

IBS is a disorder affecting the large and small intestine. It can cause cramping, abdominal pain, bloating, gas, and diarrhoea, constipation or both.

IBS is called a 'functional disorder' as it affects the function of the intestine even though there are no obvious physical changes in the body to explain why it occurs.

There is unlikely to be a single cause. Factors that might contribute to IBS include:

- different levels of muscle activity in the wall of the intestine - they may contract more strongly or less strongly than usual
- differences in how a person perceives normal muscle contractions and stretching of the bowel
- an attack of gastroenteritis or other infection in the past (accounting for about 25% of cases)
- stress and anxiety
- food intolerance
- changes in the bacteria which are normally present in the intestine.

Due to the pelvic floor involvement in the mechanisms of continence, in IBS the pelvic floor increases its contraction to prevent us from leaking stools and, in IBS, a dyssynergic pelvic floor that cannot relax will perpetuate the cycle of IBS by inhibiting the defecatory urge and contribute to an incomplete emptying of the rectal ampoule. These symptoms are also linked with endometriosis.

How common is IBS?

About 5-10% of adults are living with symptoms of IBS. Up to 30% may have symptoms at some time in their lives. More women than men experience IBS.

What are the symptoms of IBS?

Key symptoms of IBS are:

- abdominal pain, cramping or bloating. It is usually relieved, fully or partly, by passing a bowel movement
- an urgent need to pass a bowel movement
- excess intestinal gas
- diarrhoea or constipation, or sometimes alternating bouts of diarrhoea and constipation
- mucus in bowel movements
- never bleeding
- straining at the beginning, during and at the end of defecation
- difficulties in starting a bowel motion and/or fully emptying the rectum
- dyspareunia (pain during or after intercourse) as a result of pelvic floor tension
- voiding dysfunction as a result of pelvic floor tension
- history of haemorrhoids or fissures.

Symptoms of IBS can come and go. They might sometimes improve or even disappear completely, only to return for no apparent reason.

Symptoms can be triggered by some foods (although true food allergy is rarely a cause), stress, and hormones (symptoms are worse at particular times in the menstrual cycle, similar to endometriosis).

How is IBS diagnosed?

Diagnosis of IBS is based mainly on the distinctive pattern of symptoms.

It is important to rule out other possible causes of IBS-like symptoms, such as coeliac disease, bowel cancer (especially in older patients) or colitis. However, the tests or investigations needed to exclude other conditions need to be adapted to the individual. In most cases, people with a typical pattern of IBS symptoms will need only a limited number of tests.

As symptoms of endometriosis can overlap with IBS, the possibility of endometriosis needs to be considered in women of reproductive age.

IBS should also be considered in women whose main problem is chronic pelvic pain.

Possible investigations include an antibody screening test for coeliac disease, checking for parasites and infections, and, less commonly, colonoscopy or endoscopy.

Colonoscopy is essential if you have had bowel cancer or polyps, if you have a strong family history of bowel cancer or polyps, you have any bleeding from the bowel, or if you have unexplained anaemia.

How is IBS treated?

- Understanding the condition and developing strategies to cope with it. If you have concerns that some disease may have been missed, you should discuss this openly with your doctor. Improvement in symptoms may not occur until you are confident that serious diseases have been excluded
- Identifying factors in your life which might aggravate it, such as high levels of stress or anxiety, drinking too much alcohol, medications which can cause constipation or diarrhoea, or a low level of physical activity
- Changes to your diet, which should be based on healthy eating and guided by the most troublesome symptoms (for example, constipation, diarrhoea, or bloating and excessive gas). An accredited dietitian will be able to provide clear advice, and the figure gives some general guidance. The 'FODMAPS' diet, under the guidance of a dietitian, may help to identify triggers of IBS symptoms.

A number of medications and other preparations are used in IBS:

- 'Bulking agents' like psyllium (for example in Metamucil), ispaghula husk derivatives (for example Fybogel) and sterculia-based products (for example Alvercol) can be helpful, especially for constipation
- Antispasmodics such as mebeverine (for example Colofac) can reduce pain and the need for urgent bowel motions. For best effect, antispasmodics should be taken three times a day, long-term, rather than just when there are symptoms. Other antispasmodics include Buscopan and Donnatabs
- Tricyclic compounds including amitriptyline (Tryptanol) were developed as antidepressants, but when they are used in low doses they have a separate effect on nerves and muscles in the bowel and bladder, and are often helpful in relieving pain
- If the main problem is watery diarrhoea then medications such as loperamide (Imodium) and Lomotil are often useful
- Iberogast is a mixture of nine medicinal herbal extracts that help to restore gut functioning and relieve the discomfort of IBS, especially bloating
- Some people with IBS have found that probiotics can reduce symptoms. More information is still needed on which specific organisms, and what doses, are effective.

General IBS Advice

Stop unnecessary restrictions

Don't over eat at meals

Regular meal pattern

Healthy eating

Consume plenty of fluids

Take time at meals chewing foods properly

Diarrhoea

Reduce dietary soluble fibre to tolerance level

Reducing some of the FODMAP foods may be useful

Minimise irritants (caffeine, spicy food, fatty foods, alcohol, & sweeteners e.g. sorbitol/fructose)

Constipation

Increase soluble fibre (fruits, veg, legumes, oats & barley)

Increase fluid intake

If experiencing symptoms of constipation alone increase intake of all sources of fibre (bran, fruit and veg with skins), along with fluid

Bloating/Flatulence

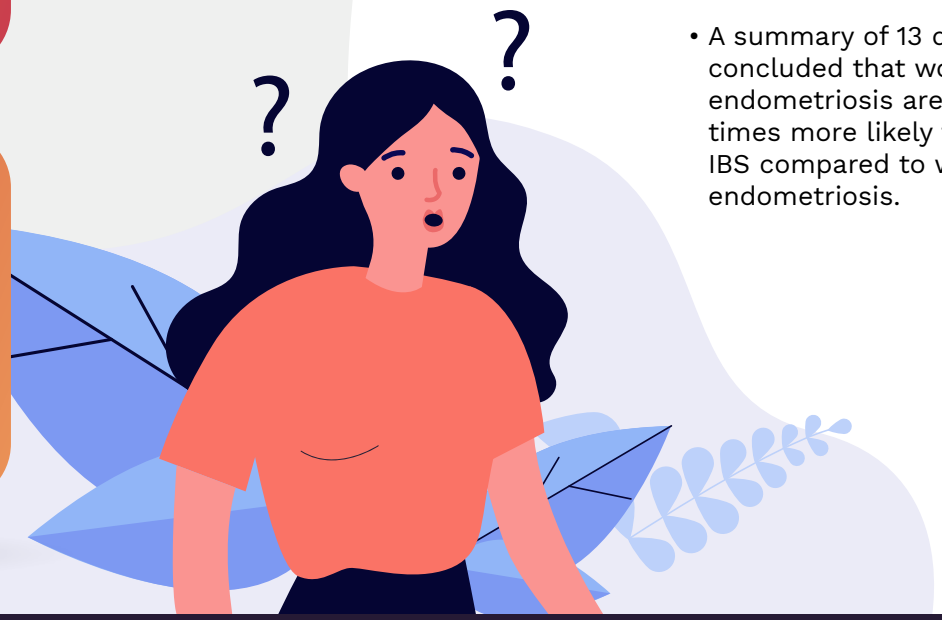
Reduce 'windy' vegetables

(brassicas, onion & pulses)

Reduce alcohol

Reducing some of the FODMAP foods may be useful

Reduce resistant starch (cooked and cooled potato, pasta, ready meals, & processed foods)



IBS and endometriosis

Health professionals might not think of endometriosis when a woman first seeks help for gastrointestinal symptoms. Symptoms such as bloating and pelvic pain can occur in both conditions.

- In an Australian study of women with suspected endometriosis, 90% had gastrointestinal symptoms and about 20% had previously been diagnosed with IBS. Bloating was the most common gastrointestinal symptom, followed by nausea, constipation, diarrhoea, vomiting and rectal bleeding.
- A summary of 13 different studies concluded that women with endometriosis are two or three times more likely to also have IBS compared to women without endometriosis.

Chronic pelvic pain

What is chronic pelvic pain?

Chronic pelvic pain is pain in the lower abdomen and pelvic region that is present on most days for six months or more. It can be a symptom of a specific disease that can be diagnosed or treated. In some cases no specific cause can be found, so the goal of treatment is to reduce pain and other symptoms and improve quality of life.

How common is chronic pelvic pain?

Estimates of the proportion of women who experience chronic pelvic pain range from 15% to 25%.

What are the symptoms of chronic pelvic pain?

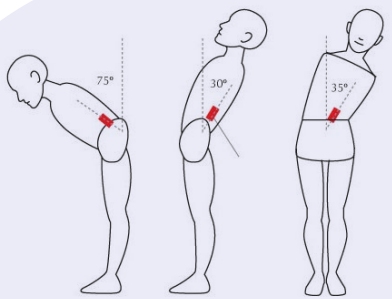
The features of chronic pelvic pain can vary widely between women. It may be felt across the entire pelvic region, but is sometimes focussed in a single spot. It can be mild or severe, persistent throughout the day or intermittent, either dull or sharp, and sometimes cause a sensation of cramping. It can be associated with pain during sex, pain while having a bowel movement or urinating, or pain when sitting for long periods of time.

How is chronic pelvic pain diagnosed?

The pathway to effective treatment of chronic pelvic pain depends on an accurate diagnosis.

Possible causes which may need to be investigated include the following:

- Period pain is very common, affecting more than 90% of women. Muscles of the uterus tighten, causing cramping or heaviness in the pelvic area, lower abdomen or lower back. It needs to be assessed in more detail if it lasts longer than a few days and does not improve despite taking pain relief or taking oral contraceptives.
- Endometriosis often causes pelvic pain, especially around the time of a menstrual period.
- Adenomyosis is similar to endometriosis, except that cells from the endometrium grow into the inner muscle layer of the uterus. Symptoms include abnormal or heavy menstrual bleeding, painful periods and painful sex.
- Irritable bowel syndrome can cause bloating, constipation and diarrhoea, which can lead to pelvic pain.
- Muscle, joint and bone pain can occur in the pelvic region. Conditions that can cause problems include pelvic floor muscle tension, inflammation of the pubic joint, and pain affecting the lower spine.
- Urinary tract infections (UTIs) are very common in women and typically cause a burning pain when passing urine, often with more widespread pelvic or lower abdominal pain.



- Interstitial cystitis (painful bladder syndrome) causes recurrent pain and a frequent need to urinate. Pain often increases as the bladder fills up, and then reduces as the bladder is emptied.
- Psychological factors such as depression, stress or a history of abuse can increase the risk of all types of pain. Emotional distress can worsen pain, which in turn worsens the distress, leading to a vicious cycle.
- Some pelvic pain is due to low back problems and can be reproduced by bending to the right or left or hyperextending. There may also be tenderness over the sacroiliac joints. Physiotherapy is the answer.

The tests and investigations used to diagnose a specific cause of chronic pelvic pain will depend on each woman's pattern of symptoms, history of problems and other individual considerations.

They might include a physical examination, laboratory tests, ultrasound and other imaging such as CT or MRI, and perhaps laparoscopy to check for conditions such as endometriosis.

Remember, though, that a clear explanation might never be found.

How is chronic pelvic pain treated?

If it is possible to pinpoint a specific cause, such as endometriosis or IBS, then treatment will focus on that cause. If a cause cannot be identified, then treatment is likely to include a number of strategies to reduce pain and improve quality of life. For many women, the best outcomes will require a multidisciplinary team providing a combination of treatments.

Medications may be recommended, depending on the cause:

- Pain relievers are often the first step, starting with over-the-counter products and then trialling prescription products if needed. However, pain relievers alone a rarely a complete solution
- Hormonal treatments including oral contraceptives can help relieve pain that is associated with the menstrual cycle
- If an infection is identified as a cause, then it might need antibiotic treatment
- Some antidepressants can be helpful for chronic pain, even for people who are not depressed
- Medications for endometriosis and IBS have been discussed earlier.

Other approaches to treatment include physiotherapy (once again, focussing on the cause), trigger-point injections of long-acting anaesthetic (if a specific trigger point can be found), and psychological therapies to reduce anxiety and develop strategies to cope with persistent pain.

Olivia Briggs, aged 26, is well acquainted with the issue of chronic pelvic pain.

Starting at 11 at the commencement of menstruation, her pain was so severe that she regularly experienced cramping, fainting and vomiting.

It was not until she was 18 that she was finally diagnosed with endometriosis.

"Not knowing what was wrong with me and being told I just had 'bad periods' was really tough," she says. "It was a relief to be able to put a name to my pain and to find a way forward. It turned out I was riddled with endometriosis from my uterus to my diaphragm. No wonder I was in so much pain!"

Olivia's experience of seven years from the onset of symptoms, to a diagnosis of endometriosis is right on average according to a study by Oxford Academic*.

Olivia is unfortunate to have a range of other health conditions, two of which are irritable bowel syndrome and chronic pelvic pain. She says she can't remember when she last had a day without pain.

"It's hard to hold down a job when you have to take so much time off for flare ups or surgeries," she says. "My present employer is very understanding, but in the past, I have had to leave jobs where they either didn't believe me, or they couldn't afford to give me more time off.

People don't really understand Endometriosis and Irritable Bowel Syndrome and I have had to educate a lot of people about the conditions. It's also expensive and socially difficult, but through pain therapy, I have learnt to master my thinking and reshape how I live with my pain. It's a part of me, but it does not define me.

"For so long I doubted myself and what my body was telling me, but getting official diagnoses really helped to understand my conditions and find ways to live with them. I have developed true grit and resilience and I'm proud to say I hiked over 800kms on the Camino de Santiago trail in Spain in 2016 - that was a real achievement.

I hope this new report from The Gut Foundation will help women like me get a quicker, more accurate diagnosis paired with the correct treatment, so they don't have to experience so many years of unnecessary chronic pelvic pain. My hope is that with education, women will be equipped with more knowledge about their symptoms so they can ask the right questions to help reduce their pain and suffering."

Elle Watmough is on a mission to educate women about getting to the bottom of chronic pelvic pain.

For years she suffered from excruciating periods which caused pain in her pelvic area, back and legs. She was told she just had 'bad periods' and there wasn't much that could be done about it.

She had also been trying unsuccessfully to get pregnant for four years and went through 10 IVF procedures.

Finally, after doing her own extensive research, she asked her doctor if endometriosis might be the problem. Investigative surgery revealed that was indeed the case and she had such bad endometriosis that some of her organs had fused together.

Following a seven-hour surgery to remove the endometriosis, Elle fell pregnant on her 11th IVF cycle and her daughter Jagger, (now aged four) was born.

"I want girls and women to know that menstruation pain shouldn't be agonising, and if it is, then ask your doctor if it might be endometriosis or some other issue such as irritable bowel syndrome causing of your pain," says Elle.

"Once I knew what the problem was, at least I could do something about it," says Elle. "It would have saved me and my husband, Anthony, years of angst, heartache and many thousands of dollars had I been accurately diagnosed in the first place.

We absolutely adore and love Jagger, but I can't bear to go through the whole IVF process again, so we won't have any more children. I hope with more education, that women will be empowered with knowledge to ask the pertinent questions about their health, so they can start to get on the road to recovery, or at least to access the right treatments to lessen their suffering."

The Gut Foundation's mission is to improve the digestive health of all Australians.

Through this mission we aim to prevent gastrointestinal conditions and disease through research and increased awareness about prevention, detection and treatment.

Founded by Professor Terry Bolin & the Gastroenterological Society of Australia in 1983, The Gut Foundation was created to help in the prevention of disease through research and education.

The Foundation is a not for profit organisation specialising in research and education into all aspects of gastrointestinal and digestive health, for both the public and fellow medical practitioners.

The Gut Foundation works with researchers and health professionals all over Australia, to build awareness, improve community understanding, educate, improve screening for digestive diseases, improve standards in practice and research and to engage in, and encourage, scientific research in relation to digestive disease.

The Importance of digestive health:

The complexity of the gut and its importance to our overall health and well being is a topic of increasing research in the medical community.

Largely responsible for the critical functions of the body's digestive and immune systems, beneficial bacteria in your digestive system have the capability of affecting your body's vitamin and mineral absorbency, hormone regulation, digestion, vitamin production, immune response as well as your body's ability to eliminate toxins.

Our educational and medical efforts focus on primary prevention through recommended dietary and lifestyle changes for all.

The Gut Foundation Board.

Our Board is made up of Gastroenterologists and a number of professionals from various fields, that are dedicated to improving the digestive health of all Australians through the treatment and prevention of gastrointestinal diseases and conditions.

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